



Experiences of family of individuals in a locked in, minimally conscious state, or vegetative state with the health care system

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3 **Experiences of caregivers of individuals in a locked in, minimally conscious state, or**
4 **vegetative state with the health care system**
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6 Sarah EP Munce PhD^{1,2,3,4}; Fiona Webster PhD⁵; Jennifer Christian MSc⁶; Laura E. Gonzalez-
7 Lara PhD⁷; Adrian M Owen, PhD⁷; Charles Weijer MD PhD⁷
8
9
10
11

12 1 University Health Network-Toronto Rehabilitation Institute, Toronto, Ontario, Canada.

13 2 Occupational Science & Occupational Therapy, University of Toronto, Toronto, Ontario,
14 Canada.

15 3 Rehabilitation Sciences Institute, University of Toronto, Toronto, Ontario, Canada.

16 4 Institute of Health Policy, Management & Evaluation, University of Toronto, Toronto, Ontario,
17 Canada.

18 5 Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada.

19 6 Centre for Addiction and Mental Health, Toronto, Ontario, Canada.

20 7 The Brain and Mind Institute, Western University, London, Ontario, Canada.
21
22
23

24 *Corresponding Author:
25

26 Dr. Sarah Munce, PhD

27 Scientist and Assistant Professor (Status Only)

28 Toronto Rehabilitation Institute-University Health Network

29 345 Rumsey Road

30 Toronto, Ontario, Canada M4G 1R7

31 Telephone: 416-597-3422 ext. 5313

32 Email: sarah.munce@uhn.ca
33
34
35

36 **Sarah Munce, PhD** is a scientist at Toronto Rehab and assistant professor (status only) at the
37 University of Toronto. Her program of research relates to developing, evaluating, and
38 implementing transitional care interventions for individuals with neurological conditions and
39 their families. **Fiona Webster, PhD** is an Associate Professor in the Arthur Labatt School of
40 Nursing, Faculty of Health Sciences, Western University. Her work focuses on the chronic pain
41 management in family medicine from both provider and patient perspectives. **Jennifer**
42 **Christian, MSc** is a Senior Project Manager at Think Research. Her work focuses on finding
43 new ways to support patients, caregivers and clinicians as they engage with the health system.
44 **Laura Gonzalez-Lara, PhD** is a Community Research Coordinator at BrainsCAN at Western
45 University. **Adrian Owen, PhD, OBE** is neuroscientist at Western University. He has
46 conducted extensive research in the area of neuroimaging with individuals in a vegetative state.
47 **Charles Weijer, MD, PhD** is a Professor in the Department of Philosophy at Western
48 University. His academic interests center on the ethics of medical research.
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Experiences of family caregivers of individuals in a locked in, minimally conscious state, or vegetative state with the health care system

Abstract

Primary Objective

The objective of the study is to understand the experiences of caregivers family members of individuals in a locked-in state (LIS), minimally conscious state (MCS), or vegetative state (VS) with the health care system when caring for their family member.

Research Design

The study adopted a qualitative descriptive approach drawing on central tenets of constructivist grounded theory described by Charmaz. Our analysis drew on emphasizing connections between theory, concepts, and empirical data using a constant comparative method.

Methods and Procedures

Semi-structured interviews were conducted with family members of individuals in a LIS, MCS, or VS. Participants were recruited between June 2014 and December 2016.

Main Outcomes and Results

A total of 22 interviews were conducted, which comprised interviews with 12 caregivers family members. The following themes were identified: care coordination challenges, lack of flexibility in health care policies, and inappropriate care settings.

Conclusions

Family member Caregivers of individuals in a LIS, MCS, or VS described playing a significant role in the lives of their family member. Based on the results of this study, flexibility in health care policies and/or programming should be adopted in the face of the challenges identified. To address the unmet needs and related burden of caregivers, implementation of interventions to support caregivers and transitions becomes is increasingly important.

Word Count=200199

Keywords: vegetative state; caregivers family members; caregivers; health care system; qualitative

INTRODUCTION

Both vegetative state (VS) and minimally conscious state (MCS) are classified as disorders of consciousness (DOCs). Patients in a VS are in a state of apparent wakefulness but they are not able to show awareness of themselves and their environment (1). People in a MCS are able to demonstrate marginal evidence of awareness such as following simple commands and using objects functionally (2). A locked-in state or syndrome (LIS) is characterized by complete paralysis with voluntary eye movement control, eye blinks, or movements of the lip (3). The incidence and prevalence of VS is rising with advances in the surgical and critical care management of patients with severe brain injuries, which are able to keep individuals alive who may otherwise have died (4). International data indicate an incidence of VS that varies from 0.5-4/100,000. Data on the prevalence of VS are even more variable from 0.6-10/100,000 (5). Given the complex needs of individuals in a VS or MCS, they require continual support from formal and/or informal caregivers, especially family members.

A limited number of studies have focused specifically on the family members/caregivers of individuals with DOCs and have described the burden that they experience (6-8). This research suggests that in the months post-event, caregivers experience anxiety, guilt, depression, and anger (9). Other studies have also described decreased hope of recovery and increased grief on the part of family/caregivers (7, 10-11). In a sample of caregivers of individuals with DOCs, Leonardi et al. (8) demonstrated that the participants had lower scores in physical and mental health and a higher level of anxiety in comparison to a normative sample. Furthermore, more than half of the participants demonstrated a high level of depressive symptoms (60%) and approximately 28% satisfied the criteria for prolonged grief disorder. This study also indicated

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2
3 that more than 75% of participants reported six perceived needs of the Caregiver Needs
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5 Assessment that related to information and communication including the need to be informed by
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7 physicians and other health care professionals about plans for the patient (93%), involved in
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9 decisions that affect the patient (90.2%), able to communicate adequately with all members of
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11 the health care team (88.3%), able to easily contact the staff involved in the care of their relative
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13 (87.3%), cognizant of what problems may develop over the course of the disease (85.6%), and
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15 enabled to perform tasks related to the care of their relative (83.2%) (8). Similarly, in
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17 individuals with severe traumatic brain injury, Doser and Norup (2016) determined that higher
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19 burden was observed in caregivers of patients with more severe injuries, who devoted more time
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21 to caregiving activities and described more unmet needs. Overall, spouses reported higher levels
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23 of burden than parents and they also took more time taking care of their family member (12).
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25 However, the issues may be worse or different for persons with DOC due to the individual's
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27 inability to speak on his/her own behalf. Collectively, tThese identified needs suggest some gaps
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29 in the health care system that may be contributing to burden among the family members of
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31 individuals with DOC, and to the best of our knowledge, no studies to date have examined these
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33 family memberearegivers' experiences with the health care system, specifically. Thus, the
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35 objective of this study was to understand the experiences of earegivers-family members of
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37 individuals in a LIS, MCS, or VS with the health care system when caring for their family
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49 METHODS

50 *51 Design/approach*

This study adopted a qualitative descriptive approach drawing on central tenets of constructivist grounded theory described by Charmaz (132). This approach emphasizes reflexivity focusing on understanding participants' experiences and how they assign meaning to these experiences by gathering rich data obtained through in-depth interviews. Data collection is aimed at discovering and exploring a participant's experiences and analysis is aimed at making sense of these experiences (132). Given the geographic diversity of the study participants, most of the interviews were conducted by telephone. Research ethics approval was obtained from Western University (Protocol Reference #104684) and the University of Toronto (Protocol Reference #30085) (blinded for review). All participants provided informed consent prior to the interview.

Recruitment

We recruited family members acting as the surrogate decision maker for patients participating in an ongoing neuroimaging research program on ~~serious brain injury~~DOCs at Western University. Typically, family members of patients are referred to the neuroimaging study by a physician or case manager and their first contact is with a research associate (LGL). For the current study, ~~family member~~caregivers had to be fluent in English to participate in the interview, have a family member with a current diagnosis of LIS, VS, or MCS, with the family member's injury occurring at least one year ago. ~~Caregiver~~Family member participants were recruited in person between June 2014 and December 2016. Recruitment ceased as the study approached the point of data saturation, which is the point when successive interviews become repetitive and no new responses or themes emerged (143).

Data collection

Each participant took part in two semi-structured, one-on-one interviews lasting approximately 60-75 minutes. The majority of interviews took place by phone; one interview was in person. For the first interview, the topic areas of the interview guide were: relationship with patient, patient's current medical condition, relationship with care providers, key decision-making moments, experiences of being with the patient, reasons for participating in research. The second interview took place after the neuroimaging results were shared. The topic areas included: The purpose of the first interview was to gain insight into the caregiver's knowledge of the patient's medical condition, their beliefs about the patient's cognitive capacities and prognosis, their reasons for enrolling the patient in research, and his/her expectations regarding EEG and functional MRI to detect preserved cognitive capacities reflections on first interview, experiences of participation in the study, study results, impact on beliefs, and recommendations to other families. Both interview guides consisted of warm up/establishment of rapport and closing/winding down sections. The second interviews were conducted at the conclusion of the research study (i.e., after the neuroimaging results were shared), to learn about the caregiver's experience during the study, how he/she understands the information that was presented to him/her, and his/her suggestions as to how the process could be improved. The topic areas from the first interview guide, especially the topics of relationship with patient, patient's current medical condition, relationship with care providers, key decision-making moments, experiences of being with the patient provided rich sources of data for the current study.

Most of the interviews were conducted by the first author. S Munce is a female, PhD-level researcher with a background in health services and knowledge translation. She had no relationship to the study participants prior to the study commencement and similarly the study participants had no knowledge of the interviewer prior to the study commencement.

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3 The interview guides consisted of semi-structured open-ended questions and were pilot
4 tested with a scientist experienced in qualitative methods. Given the sensitive nature of the
5 topic (e.g., beliefs about a family member's cognitive capacities and prognosis), we were careful
6 to develop guides that began with the establishment of rapport, moving through to more personal
7 questions slowly. Probes or recursive questioning were used during interviews to explore issues
8 in greater depth and verify the interviewer's understanding of the information being collected
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17 (143). [See Supplemental File 1 for the interview guides used.](#) All interviews were digitally
18 recorded and transcribed verbatim for data analysis.
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21 ***Data analysis***

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24 Reflective notes from the interviews, as well as the transcripts were entered into NVivo 9
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26 (14). In grounded theory, emergent themes are not just used to explore an issue, but also to
27 construct a cohesive idea or theory about an investigated phenomenon. Our analysis drew on
28 emphasizing connections between theory, concepts, and empirical data using a constant
29 comparative method. Our data analysis occurred in the following steps: coding, memoing,
30 member checking, and theory/model formulation. Following verification of the accuracy of the
31 transcripts by the interviewer, all members of the research team read all of the transcripts
32 independently to become familiar with the data. The core research team then met as a group to
33 discuss initial codes, giving full attention to all data. *Codes* identify features of the data that are
34 pertinent to the research questions and organize data into more concise ideas that can be
35 eventually grouped into themes; [overall codes emerged over the course of the analysis process.](#)
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49 *Open coding* was performed to get a more general feel for the content of the data. During *axial*
50 *coding*, relationships are explored between these codes and *selective coding* involves integrating
51 these codes or concepts into a core explanatory theory. Following this, the codes were clustered
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3 into groups that shared similar meanings. During these meetings, differing views and opinions
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5 between team members were fully explored as a strategy to remain reflexive during our analysis.
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7 The research team then met to discuss the coding as well as the data assigned to the codes and
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9 themes/sub-themes. New themes and sub-themes were identified. The research team explored
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11 various thematic maps until consensus was reached. One member of the research team (JC) then
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13 applied this framework to all of the transcripts.
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21 RESULTS

22 *Description of Participants*

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24 A total of 22 interviews were conducted, which comprised interviews with 12 caregivers
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26 family members (spouses, parents, and a sibling) both before and after they received the results
27
28 of the neuroimaging tests. All of the participants were listed as the next of kin; 2 participants
29
30 had power of attorney; 6 participants were listed as the substitute decision maker or legal
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32 guardian. Characteristics of the patients and caregivers-family members are reported in Table 1.
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37 [Table 1 near here]
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40 *Overview of Themes*

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42 The following themes corresponding to the core category of family membercaregivers of
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44 individuals in a LIS, MCS, or VS as they interacted with the health care system were identified:
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46 care coordination challenges, lack of flexibility in health care policies (including jurisdictional
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48 challenges in the care/policies between provinces), and inappropriate care settings. Across these
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50 inter-related themes, a common factor was the need for the caregiver-family member to act as a
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52 mediator between the patient and a health care system that is rigid. Quotes exemplifying each
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3 theme have been included below. The quotes are identified with their number and an A or a B to
4 indicate if the interview occurred before or after the participant received the neuroimaging
5 results, respectively.
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8 9 10 *Care Coordination Challenges*

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12 Many of the participants outlined care coordination challenges and specific difficulties
13 they encountered in organizing home care from Community Care Access Centres (CCACs). For
14 example, one participant, whose husband was staying in hospital, wanted to determine whether
15 she could care for him at home with CCAC support. To test this possibility, she had asked
16 whether she could bring her husband home on the weekend with CCAC visits. This participant
17 was told that this was not possible as her spouse was still in hospital; this decision extended the
18 amount of time her spouse remained in the acute care setting. Many ~~caregiver~~ family member
19 participants described how they acted as a care coordinator and advocate to overcome similar
20 challenges. This participant outlined how her proposal was not only her preference but that it
21 would represent cost savings to the health care system:
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35 *And I have been pushing very hard to get him home. I have even approached the hospital*
36 *team, the CCAC, and said, you know, "Can we try, in a transitional way, for him to come*
37 *home on weekends, overnight, and can you guys give me the support I need to make that*
38 *happen?" and I'm being told no, because as long as he's in the hospital he doesn't get*
39 *CCAC. But my point is how do I know if I can manage this without trying it out?*
40 *(Interview #1A)*
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44 She reflects specifically on the lack of integration between various sectors of the health care
45 system, noting "I want to bring him home; I'm thinking it's helping the system, why won't you
46 help me?" She continues, describing the work that she must perform to link various care
47 providers:
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54 *Like, I'm not understanding those breakdowns that clearly, in my opinion, is [sic] just a*
55 *breakdown in the system, right? Everybody's getting paid but why aren't they all*
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3 *integrating? Why are they not... why is there no synergy between all these different*
4 *groups, right? Like, if I have to talk to the OT about something I can't tell the nurse, I*
5 *have to make time to find an appointment with the OT to talk to her about it. Like, these*
6 *things just don't make sense to me. It's like shouldn't there be a coordinated effort for*
7 *people like [patient]? (Interview #1A)*
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11 Another participant^s recounts how she was offered no help or support in transferring her family
12 member home, stating, “*They wouldn't help us at all. Like, they wouldn't even lend us a*
13 *wheelchair or anything, we had to supply everything ourselves*” (Interview #6A).
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17 Similarly, this mother recounts how she attempted to set up an informal network with three other
18 mothers through which they could share information. However, she states that
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22 *... If I had something that was working with my daughter I would share it for their son,*
23 *and we did that but sometimes it required support from CCAC, and the same with them.*
24 *... But CCAC, we had the... we've had really tough, tough dealings with them over the*
25 *years. They leave us alone now, we're almost like an island unto ourselves ... (Interview*
26 *#6A).*
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30 As previously reported, in performing caregiving tasks such as care coordination, many
31 participants described the role as a duty and indicated specifically that caregiving for a person in
32 a LIS, MCS, or VS resulted in financial, emotional, social, and marital strain. Family
33 memberCaregiver participants indicated that they served multiple roles and that these roles were
34 often in conflict with each other (15). Participants also indicated that different stages were
35 associated with different strains. For example, in the more chronic stages, caregiver-family
36 member participants often described financial and marital strain. Participants described social
37 support as being present in the acute stage of the injury, but generally absent several years post-
38 injury (i.e., beyond core family members). Across all stages, participants described emotional
39 strain. The financial impact of taking on these caregiving responsibilities, specifically care
40 coordination, is exemplified in the following quote:
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3 ... I gave up my work – I'm an IT consultant, an IT guy for all my career – but I gave that
4 one up and I said, "Look, I have to take care of my wife." So from that perspective, as I
5 said, I was micromanaging from all aspects of the treatment. (Interview #4A)
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8 9 Lack of Flexibility in Health Care Policies

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11 Participants described a lack of flexibility in health care policies including jurisdictional
12 challenges between provinces when family members suffered their injuries had their events in
13 one province and needed care or had family to provide care in another province. Family
14 memberCaregiver participants emphasized the need for advocacy in the face of this lack of
15 flexibility in health care policies and that small changes or flexibility in certain policies could
16 have a substantial impact on the quality of life of the family membercaregivers and patients.
17
18 This theme is encapsulated in the story below, in which one caregiver family member describes
19 being given a short amount of time to make decisions that would have a significant impact on her
20 and her family's lives and also involved being present in a different province from where they
21 lived:
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34 ...well, it's just that you're in Ontario, so you've given 24 hours to say yes or no to the
35 bed, and then you're given five days to actually be physically there...So we just said,
36 "Well, that's absolutely impossible for us, because we can't organize our lives like that."
37 You know, we'd been out an [Canadian City] for two years, we've got, ...rental
38 obligations, we've got people living in our house in Ontario...(Interview #2A)
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41 This mother further described a situation where her son had medical issues that required him to
42 leave the nursing home but then had to return onsite to the nursing home after 45 days (even if
43 his medical issues had not resolved) to keep the nursing home bed:
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48 ...generally you can be away from your long-term bed usually, I think they now allow,
49 like, maybe three weeks, for a medical issue, and still keep your bed, but because
50 [patient], he's gone in under, like, a mental health issue, you're allowed, like, 45 days
51 that you can be away from your bed and still keep it, Okay? But he has to come back
52 every 45 days just to show his face at [Nursing Home] in [Nursing Home] and then go
53 back up to [City]. So, I mean, it's such a... so he's still paying for his bed, right, in
54 [Nursing Home], you know, \$1800 a month. So anyways, the first 45-day cycle kind of
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was around Christmas, which was perfect, so we went up to [City] to pick him up, and then he was in [Nursing Home] for three or four days, then we took him back up to [City]. And I've since heard – I mean, I don't know the avenues or the routes that are being taken, but permission has been given, [patient] can do as many 45-day cycle turnarounds as is deemed necessary" (Interview #2B)

In contrast to the overall lack of control family member caregivers experienced because of this inflexibility, generally, participants indicated that receiving the results from the accompanying neuroimaging study provided them with some control as well as hope and clarity. These benefits are encapsulated in the quotes below:

At least with this [testing] we know where we stand and what is going on with him, so that we... when somebody asks, you know, at least we have something that we can explain to them, "Okay, there was a bit of activity. There's not much we can do. We can't expect too much. Let's just, you know, hope for the best (Interview #5B)

...so it's kind of nice to know these kind of things because then... you know, and then if somebody asks me, you know, like if this doctor that I decide to do the sleep testing with or something like that, he says, "Well," you know, "why do you know this?" or, "How do you know this?" and I can say, "Well, I have this report that was given to me, and I had an inclination that there was something wrong with him sleeping, but it's been confirmed," and then I can kind of show. So it is nice to have that... (Interview #9B)

Inappropriate Care Settings

Many of the participants indicated that the settings where their family members were receiving care were inappropriate. For example, many of the individuals in a LIS, MCS, or VS were young people and were residing in a long-term care home with older individuals with dementia/Alzheimer's disease. Furthermore, many family member caregiver participants also indicated that their preferred setting for their loved one would be at home but expressed anxiety about not being able to adequately care for them at home or not having adequate support services including a lack of flexibility in the policies of home care services. This theme is exemplified in

the following account in which a family member describes the ‘limbo’ of meeting the eligibility criterion for either rehabilitation or long-term care:

... some of the rehab centres – or most of them – they don’t accept somebody at [patient]’s level, right? He’s not self-sufficient enough... So there’s kind of a limbo or grey area... not even grey, it’s just a gap, right, in the system. There’s nothing in between... like a rehab hospital and a long-term care facility, there’s nothing in between that can help people... And then the long-term care facilities, they’ve cut back on their physio... (Interview #3B)

This theme also had overlap with the lack of flexibility in healthcare policies such that existing policies did not support the preferred care settings of the patient’s families:

So because I’ve not been successful at rehab, I’m like, “You know what? I’m just going to bring him home.” But I’m not getting help to do that either. So the hospital’s asking me to talk to CCAC. Well, when I talk to CCAC they’re telling me, “We can’t do that transitional,” so I’m like, “Okay, so where do I go? I mean, where do I go?” I’m trying to help, and I’m thinking it’s a win for the hospital, it’s a win for the system, it’s a win for [patient], he’s going to come home, but I’m being told everywhere... and then I’m being told long-term care. No, that’s not where he should be going, because he’s making small progress... (Interview 1A)

DISCUSSION

The objective of the current study was to understand the experiences of family membersearegivers of individuals in a LIS, MCS, or VS with the health care system when caring for their family member. To the best of our knowledge, this is the first study of the experiences of the health system challenges identified by the family membersearegivers of individuals in a LIS, MCS, or VS.

The following themes were identified in relation to the core experience of families’ interaction with the health care system: care coordination challenges; lack of flexibility in health care policies; and inappropriate care settings. Across these themes, the need for the family member-caregiver to act as an advocate and mediator between the patient and health care system that is rigid. Indeed, in a mixed methods study on the informal networks (family

members/caregivers) for individuals with spinal cord injury, Guilcher et al. (16) demonstrated that these informal networks serve an essential role in filling the gaps that exist within the formal health care system. In the current era of patient-centeredness in clinical practice and policy, we noted how many of the experiences our participants described seemed more system-centred (i.e., designed not around patient and ~~caregiver~~ family member needs but around the needs of care organizations, from hospitals to rehabilitation and long-term care). At the same time, these organizations rely on the work of family members, as noted above, work that is often unacknowledged and yet central to the provision of good care. ~~At the same time,~~ it is also argued that patients may not be receiving best possible care when delivered by untrained personnel (i.e., the ~~caregiver~~ family member). Epstein et al. (17) identify that while patient-centered care is acknowledged by clinicians as an ideal approach to care provision, “what it is and how to measure it” is not clear to clinicians. While some research has identified main areas of patient-centred care including effective communication (i.e., sharing information, compassionate and empowering care provision, sensitivity to patient needs), partnership (i.e., relationship building, interprofessional collaboration), and health promotion (i.e., effective case management, efficient use of resources) (18-19), Epstein et al. (17) suggest that additional research is needed to reinforce the evidence supporting patient-centered care in healthcare. Lastly, many of the areas identified as key components of patient-centred care were absent in the experiences of family member~~caregivers~~ of individuals in a LIS, MCS, or VS with the health care system, as further discussed below (e.g., lack of sensitivity to patient needs, ineffective case management) (18).

The care coordination challenges identified in the current study have been identified previously in one component of the National Population Health Study of Neurological

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3 Conditions (NPHS-NC) (20). This study comprised 180 interviews with health care
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5 professionals, community-based non-health care professionals, and policy makers on the health
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7 and community service needs and gaps in care for persons with neurological conditions (across
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9 16 conditions). Gaps in community integration were identified, specifically in the areas of
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11 caregiver support, life enhancing resources including education, employment, housing, and
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13 transportation, and supported transitions. With respect to the latter component, and similar to the
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15 current findings, gaps were between inpatient care and community services were identified. For
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17 those with dementia and amyotrophic lateral sclerosis, specifically, there was a need for case
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19 coordination, protocols, and overall support for transitions to long-term care (20). Furthermore,
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21 participants frequently highlighted the importance of informal caregiving and the specific roles
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23 of the caregiver when caring for an individual with a neurological condition including case
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25 manager and advocate, as identified in the current study. In the NPHS-NC, a number of unmet
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27 needs for informal caregivers were identified that related to these roles, such as training and
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29 education to prepare them for their role and to help them promote independence and
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31 empowerment to navigate the health care system (18). Participants in the NPHS-NC study, as
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33 well as the current study, identified high caregiver burden as a result of these roles and unmet
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35 needs. This family member/caregiver burden identified and described by the participants in the
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37 current study is documented and discussed in a related paper (15). To address these unmet needs
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39 and related burden, implementation of interventions to support ~~caregivers~~ family members and
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41 transitions is increasingly important. These support services could include assistance completing
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43 government forms, home support services, respite care options, and opportunities for peer
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45 support (20-21).
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Participants also described a lack of flexibility in health care policies, including jurisdictional challenges between provinces. This challenge was also identified in a recent study on the perspectives of stakeholders on the availability of and access to prescription drugs for individuals with neurological conditions in Canada (22). The authors demonstrated that there were substantial differences in drug coverage and related policies among the Canadian jurisdictions for individuals with neurological conditions. Specifically, participants identified concerns with respect to the lack of standardization among Canadian jurisdictions as to which drugs were publicly covered under the provincial and territorial formularies. Furthermore, in a systems analysis of community and health services for acquired brain injury in Ontario, Canada, the need for flexibility in health care policies and/or programming was also identified and it is argued that such flexibility should be adopted in the face of challenges, including those identified in the current study. Furthermore, flexibility was seen as critical in developing innovative and effective programs for individuals with brain injury (23). The need for flexibility for ~~caregivers~~ family members of individuals in LIS, MCS, or VS, as identified in the current study, is consistent with the findings of the NPHS-NC study whereby participants highlighted the need for person-centred care. This outlook may involve the application of integrative case planning and services and supports in the community to facilitate smooth transitions across health care settings (e.g., from hospital to the community or from the home to long-term care admission) (20). It should be noted these experiences were in contrast to the generally positive experiences ~~caregiver-family member~~ participants had when interacting with the research staff for the accompanying neuroimaging studies and receiving the results. Participants described feeling some sense of control, hope, and clarity after receiving the test results.

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Lastly, inappropriate care settings were identified by the caregiver-family member participants in this study, whereby many of the individuals in a LIS, MCS, or VS state are young people residing in long-term care homes with elderly individuals. A lack of specialized services and programs for children and adolescents with brain injury has been identified previously, with adolescents/young adults receiving care at unsuitable and inappropriate environments such as aged care facilities (23). This phenomenon has also been previously demonstrated by Cameron (24) and Slomine et al. (25), although participants in the current study have resided in long-term care homes for much longer.

We acknowledge some limitations. In terms of the recruitment procedure, it is likely that a selection bias operated in those participants who agreed to take part in the research – they may have been more informed health care consumers than those individuals who chose not to participate. The majority of caregiver-family member participants in the current study were female. Future research should attempt to focus on the perspective of male caregivers-family members to increase the applicability of the study findings. Most of the participants in our study were caregivers-family members of individuals in a VS; thus we are unable to make any comparisons between caregivers of persons in a LIS, MCS, or VS. Future research should seek to examine whether any differences in the experiences of these caregivers-family members exist. Similarly, future studies may pursue purposive sampling based on time since injury to explore how/if differences exist.

It is unknown whether the findings of the current study would emerge in other developed regions such as the US or Europe; however, we anticipate that countries with a similar health care system to Canada (e.g., Australia), including universal health care, might have similar issues. It is possible that a universal health care system allows less opportunities for

personalization and therefore issues of coordination, flexibility in policies, and inappropriate care setting emerge. Future studies should seek to replicate this study in similar and dissimilar health care contexts. Finally, future research could also seek to explore the health system challenges encountered by ~~caregivers~~ family members in the acute stage of recovery, although participants in the current study were able to recall challenges that they faced at this time.

CONCLUSIONS AND IMPLICATIONS

~~We noted the significant role that caregivers~~ amily members of individuals in a LIS, MCS, or VS in the current study described playing a significant role in the lives of their family member. Specifically, ~~;~~ they described acting as a mediator between the patient and a health care system that is rigid. Based on these results, ~~w~~We argue that flexibility in health care policies and/or programming should be adopted in the face of the challenges identified. Specific patient-centred models should be introduced which focus on key components such as communication, partnership, and health promotion. Additionally, to address the unmet needs and related burden of ~~caregivers~~ family members, implementation of interventions to support caregivers and transitions becomes increasingly important. These support services could include home support services, respite care options, and opportunities for peer support.

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Table 1. Characteristics of Patients and Caregivers

Participant	Relationship to patient	Time since injury (years)	Setting of patient care	Diagnosis
P1	Wife	5	Hospital	VS
P2	Mother (son)	4	Long-term care facility	MCS
P3	Father (son)	17	Long-term care facility	VS/MCS
P4	Husband	1	Hospital	VS
P5	Wife	3	Hospital	VS/MCS
P6	Mother (daughter)	22	Home	VS
P7	Wife	1	Hospital	LIS
P8	Mother (son)	1	Hospital	VS
P9	Father (son) & Sister	1	Hospital	MCS/EMCS
P10	Father (son)	3	Long-term care facility	VS
P11	Mother	2	Home	VS

Impact of neuroimaging on the families of vegetative and minimally conscious patients after serious brain injury

Principal investigator: Charles Weijer
November 17, 2013

Semi-structured interview guide: first interview

Please note that this guide only represents the main themes to be discussed with the participants and as such does not include all the various probes that may be used. Non-leading prompts will also be used, such as “Can you please tell me a little bit more about that?” and “What does that look like for you” when probing abstract claims or statements.

Warm-up and establishment of rapport

Thank you for agreeing to participate in this interview. We are interviewing you to better understand your experiences as the decision maker for a person who is participating in a research study. So, there are no right or wrong answers to any of our questions. We are interested in your opinions.

You have signed the consent form and are aware of your rights as a participant. The interview should take approximately one to one-and-a-half hours depending on how much information you would like to share. With your permission, I would like to audio record the interview because I don't want to miss any of your comments. All responses will be kept confidential. This means that your de-identified interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you to anyone. You may decline to answer any particular question or stop participating in the interview altogether at any time and for any reason. Are there any questions about what I have just explained?

May I turn on the digital recorder?

Relationship with patient

I'd like to start by asking you to share with me your relationship with (name). I understand that (name) is your (relation). Who would you describe as his/her primary care giver?

Prompts: Are there any other family members or friends involved in his/her care? Who makes decisions on behalf of (name)? How do you feel about that?

If not self-identified as primary caregiver: What do you understand to be your primary role in relation to (name)?

Do you also have other roles (i.e., family member, care giver, and decision maker)? How do you manage these various roles? Can you give me a concrete example of a time when you felt your roles were in conflict?

Patient's current medical condition

Now I'd like to talk to you a little bit about what's happened with (name). Can you tell me a little bit about that?

Prompts: What happened to him/her? How long has he/she been here (in a hospital or at home)? Where would you like him/her to be?

Could you please describe for me your understanding of (name)'s medical condition? How do you explain it others in your family for instance?

Prompts: What is it called? What does it mean in terms of the current life of (name)? What are the prospects for recovery?

Relationship with care providers

Where do you get information about (name)'s medical condition?

Prompts: Nurses? Physicians? Neurologists? Family members or friends? Others?

How do you figure out whether a source of information is reliable?

Prompts: For example, have you ever had difficulty choosing between conflicting opinions?

Can you tell me about one of the most helpful experiences you've had with a care provider?

And what about one of the least helpful experiences?

Who do you rely on the most for support? What type of support do you feel you need?

Prompts: Nursing help? Social worker? Family? Friends?

Key decision-making moments

Can you tell me about a recent decision that needed to be made regarding his/her care?

Prompts: What happened? Who was involved?

What for you were the key decisions that needed to be made?

Prompts: How did the topic come up? How did you feel about that discussion? What was the outcome?

Experiences of being with the patient

Now I want to ask you some questions about your experiences of being with (name). How would you describe your experience of (name) when you are with him/her?

I'd like to talk to you about your experiences of (name) knowing when you are in the room—what do you think about this? What about his/her ability to feel pain or discomfort? Or when you hold his/her hand? How does that make you feel?

What are your thoughts about whether or not he/she communicates with you?

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4 How does he/she do this? What was going on that made you believe this (grimaced, responded to
5 touch, etc)?
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8 What about how you communicate with him/her? For example, sometimes people talk to their
9 family members. What is that like for you? What do you think about his/her ability to hear you?
10

11 How do others in your life react when you express your thoughts about this? Does anyone share
12 your view? Does anyone disagree (family members, physicians, nurses)?
13

14 **Reasons for participating in research**

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16
17 How did you come to the program of research on serious brain injury at Western?

18 Prompts: Did someone recommend that (name) undergo testing here? If so, what did he/she tell
19 you about the sort of testing we do here?
20

21
22 What made you interested in having him/her participate in the study?

23 Prompts: Do you think testing will benefit (name)? How? What do you hope to learn? Are you
24 hoping for anything to change (i.e., future care, medical condition)?
25

26 Are there any risks to (name) of being in this study? What are they?
27

28 Are there any risks to you or anyone else in the family of (name) being in this study? What are
29 they?
30

31
32 Do you think his/her medical condition will improve? What do you think it will be like in 1 year?
33 5 years? Do the others in your family share this view?
34

35 **Close**

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37
38 Thank you very much for speaking with me today. Is there anything else I haven't asked you about
39 that you would like to share with me?
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41 Before we end I want to explain to you what our next steps will be in this study. We will send you
42 a summary of our interview today about a week before our next meeting and then sit down and
43 speak with you again after your participation in the program of research on serious brain injury at
44 Western University.
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Semi-structured interview guide: second interview

**Families will have been provided a 1 to 2 page summary of the first interview.*

Please note that this guide only represents the main themes to be discussed with the participants and as such does not include all the various probes that may be used. Non-leading prompts will also be used, such as “Can you please tell me a little bit more about that?” and “What does that look like for you” when probing abstract claims or statements.

Warm-up and establishment of rapport

Thank you for agreeing to speak with us again. As you know, we are interviewing you to better understand your experiences as the decision maker for a person who is participating in a research study. So, there are no right or wrong answers to any of our questions. We are interested in your opinions.

You have signed the consent form and are aware of your rights as a participant. The interview should take approximately one to one-and-a-half hours depending on how much information you would like to share. With your permission, I would like to audio record the interview because I don't want to miss any of your comments. All responses will be kept confidential. This means that your de-identified interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you to anyone. You may decline to answer any particular question or stop participating in the interview altogether at any time and for any reason. Are there any questions about what I have just explained?

May I turn on the digital recorder?

Reflections on first interview

I'd like to start by asking you your thoughts about our first conversation.

What was it like to read the summary?

How well did the summary capture the main points of what you remember of our conversation?

Often people remember things they might have wanted to share after a conversation is over. Is there anything else that was left out of that first conversation that you think is important for us to know?

Experiences of participation in study

Since we last met, you went on to participate in the program of research on serious brain injury at Western University. What was it like to participate in that study?

How did you feel you were treated by the study staff?

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4 How did you feel during the process (anxious/relaxed/neutral)?
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6 Please tell me about anything that you didn't expect.

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8 Prompts: in terms of the study results; in terms of how you felt; in terms of the reactions of others
9

10 **Study Results**

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12 What was it like to receive the study results?

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14 Prompts: Who explained the results to you? Where were you? Who was with you?
15

16 What do you remember about what was explained to you?

17
18 Was there anything you wanted to know and weren't told?
19

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21 Was there anything you felt you didn't understand?
22

23 Overall, how did you feel about the study results?
24

25
26 What did you do right after receiving the results?
27

28 **Impact on beliefs**

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30 Since receiving the study results, how would you describe your experience of (name) when you
31 are with him/her?
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34 I'd like to talk to you about your experiences of (name) knowing when you are in the room—what
35 do you think about this? What about his/her ability to feel pain or discomfort? Or when you hold
36 his/her hand? How does that make you feel?
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39 What are your thoughts about whether or not he/she communicates with you?
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42 How does he/she do this? What was going on that made you believe this (grimaced, responded to
43 touch, etc)?
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46 What about how you communicate with him/her? For example, sometimes people talk to their
47 family members. What is that like for you? What do you think about his/her ability to hear you?
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50 How do others in your life react when you express your thoughts about this? Does anyone share
51 your view? Does anyone disagree (family members, physicians, nurses)?
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53 **Recommendations to other families**

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55 What advice would you give to other families considering participating in this research?
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3 Finally, thinking back on your experiences, what or who has most helped you to get through this
4 experience? What could have made it better?
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9 **Close**
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11 Thank you so much again for your valuable time in speaking with us. It is truly appreciated.
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